Maricopa County Department of Public Health

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Quality Improvement-Vital Statistics Data Sharing with Epidemiologists in Local Health Departments Survey Analysis Report

OFFICE OF EPIDEMIOLOGY

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**Introduction**

The Maricopa County Department of Public Health Office of Epidemiology created this survey to assess vital registration data sharing practices between state and local health jurisdictions as part of a quality improvement project funded by the Robert Wood Johnson Foundation. The goal of the project is to improve the timeliness of death record data flow from state health departments to data users, primarily epidemiologists in local health departments. The questions included in this survey will help us gather information about the types of death record data provided to local epidemiologists by state vital records offices. This survey was created in SurveyMonkey.com and accessed from July 23rd, 2014 till August 14th, 2014. This survey was sent to NACCHO (National Association of County & City Health Officials) newsletters, NACCHO Epidemiology work groups, CLUE (Council of Large Urban Epidemiologists) members, CSTE (Council of State and Territorial Epidemiologists) members, counties in Arizona, and Connecticut’s epidemiologist. Maricopa County Department of Public Health sent out an email on August 8th, 2014 to remind local epidemiologist to fill out the survey.

 There were 26 questions in this survey. A total of 89 respondents completed the survey questionnaire. During the questionnaire participants were asked accessibility to different types of death data (real-time or live data, individually identifiable death data, de-identified death data, aggregate statistics), timeliness of data flow, uses of death data as well as barriers to obtain access death data.

**Section1. Basic information (State, County, Name, Email, Job Title)**

The total 89 participants were from 22 different states and 66 different counties/jurisdictions. The following maps show the responses by states and jurisdictions.

**Map 1: Survey responses by StateMap 2: Survey responses by County**

**Figure 1.** The following figure shows the number and distribution of the participants’ job title. There was a 100% response rate for job title.

Of the participants that completed the questionnaire, 62 (69.7%) work as Epidemiologists, 3 (3.4%) work in the area of Environmental Health Service, and 24 (27.0%) are doing Health related work (Nurse, Biology service, Health data analyst, Health Educator, and Health Service).

**Section2. Data Set User Agreement**

**Question 6:** Does your office or program have a data user agreement with your state vital statistics office? There was a 98.9% response rate, with one response missing.

**Figure 2.** The following figure shows the percentage of answers for Question 6.

**Section3. Questions about De-identified Death Data Sets Accessibility, Timeliness of Data Flow, and How Interested in Receiving De-identified Death Data.**

**Question 7:** Does your state vital statistics office send you de-identified death data? There was a 95.5% response rate, with four responses missing.

**Figure 3.** The following figure shows the percentage of answers for Question 7.

**Question 8:** On a scale of 1 to 5, how interested are you in receiving de-identified death data from your state vital statistics office? (1=not interested, 5=very interested)

If participants answered “Yes” in Question 7, he/she would skip to Question 9; otherwise he/she would answer Question 8. There was a 100% response rate.

**Figure 4.** The following figure shows the percentage of answers for Question 8.

**Question 9:** How often do you receive de-identified death data sets? If participants answered “Yes” in Question 7, he/she would answer this question (N=28). There was a 100% response rate.

**Figure 5.** The following figure shows the percentage of answers for Question 9.

**Question 10:** What is the average time difference between receipt of de-identified death data sets and date of death? If participants answered “No” or “Don’t know” in Question 7, he/she would skip this question (N=57). There was a 96.4% response rate, with 1 responses missing.

**Figure 6.** The following figure shows the percentage of answers for Question 10.

**Section4. Questions about Real Time Death Data Sets Accessibility, Timeliness of Data Flow, and How Interested in Receiving Real Time Death Data.**

**Question 11:** Does your office or program have access to real-time or “live” death data from your state vital statistics office? There was an 89.9% response rate, with 9 responses missing.

**Figure 7.** The following figure shows the percentage of answers for Question 11.

**Question 12:** On a scale of 1 to 5, how interested are you in having access to real-time death data from your state vital statistics office? (1=not interested, 5=very interested)

If participants answered “Yes” in Question 11, he/she would skip to Question 13; otherwise he/she would answer Question 12. There was a 100% response rate.

**Figure 8.** The following figure shows the percentage of answers for Question 12.

**Question 13:** On a scale of 1 to 5, how would you rank your capacity to utilize real-time death data?

There was an 89.9% response rate, with 9 responses missing.

**Figure 9.** The following figure shows the percentage of answers for Question 13.

**Section5. Questions about Individual Identifiable Death Record Data Sets Accessibility, Timeliness of Data Flow, and How Interested in Receiving Individual Identifiable Death Record Data.**

**Question 14:** Does your office or program receive individually identifiable death record data in static (not real-time or live) form from your state vital statistics office? There was an 88.8% response rate, with 10 responses missing.

**Figure 10.** The following figure shows the percentage of answers for Question 14.

**Question 15:** On a scale of 1 to 5, how interested are you in having access to individually identifiable death record data from your state vital statistics office? (1=not interested, 5=very interested)

If participants answered “Yes” in Question 14, he/she would skip to Question 16; otherwise he/she would answer Question 15. There was a 98.9% response rate, with one response missing.

**Figure 11.** The following figure shows the percentage of answers for Question 15.

**Question 16:** How often do you receive individual identifiable death record data?

If participants answered “No” or “Don’t Know” in Question 14, he/she would skip this question. There was a 78.4% response rate, with eight responses missing.

**Figure 12.** The following figure shows the percentage of answers for Question 16.

**Question 17:** What is the average time difference between the time you receive individual identifiable death record data and date of death? There was a 76.7% response rate, with nine responses missing.

**Figure 13.** The following figure shows the percentage of answers for Question 17.

**Section6. Questions about Aggregate Statistics or Reports on Death Data Sets Access, Timeliness of Data Flow, and How Interested in Receiving Aggregate Statistics or Reports on Death Data Sets.**

**Question 18:** Does your office or program receive aggregate statistics or reports on death data sets from your state vital statistics office? There was an 86.5% response rate, with 12 responses missing.

**Figure 14.** The following figure shows the percentage of answers for Question 18.

**Question 19**: On a scale of 1 to 5, how interested are you in having access to aggregate statistics or reports from your state vital statistics office? (1=not interested, 5=very interested)

If participants answered “Yes” in Question 18, he/she would skip to Question 20; otherwise he/she would answer Question 19. There was a 100 response rate.

**Figure 15.** The following figure shows the percentage of answers for Question 19.

**Question 20:** How often do you receive aggregate statistics or reports on death data?

If participants answered “No” or “Don’t’ know” in Question 18, he/she would skip this question. There was a 100% response rate.

**Figure 16.** The following figure shows the percentage of answers for Question 20.

**Question 21:** What is the average time difference between receipt of aggregate statistics or reports on death data and date of death? If participants answered “No” or “Don’t’ know” in Question 18, he/she would skip this question. There was a 100% response rate.

**Figure 17.** The following figure shows the percentage of answers for Question 21.

**Section7. Questions about Other Type of Death Data Sets Accessibility, Uses, Barriers to obtain access to data, and Comments.**

**Question 22:** Does your office or program receive any other type of death data not mentioned above?

 There was an 84.3% response rate, with 14 responses missing.

**Figure 18.** The following figure shows the percentage of answers for Question 22.

**Question 23:** Please describe the type of death data that you receive and was not mentioned previously.

If participants answered “No” or “Don’t’ know” in Question 22, he/she would skip this question. There was a 100% response rate. This is an open text question. According to the responses, we categorized the answers into 5 different categories: Individual death certificates, Medical examiner, Child fatality review record, Multiple cause of death data set, and Death investigation.

**Figure 19.** The following figure shows the percentage of answers for Question 23.

**Question 24:** How is your office or program using death data? Please describe. This was an open text question. According to the responses, we categorized the answers into 4 different categories: Use data for Disease Surveillance/ Case Investigation/ Mortality Analyses, for Grant Application, for Health Impact Assessment, and for Evaluation of Intervention/Making Program Decision. There was a 75.3% response rate, with 22 responses missing.

**Figure 20.** The following figure shows the percentage of answers for Question 24.

**Question 25:** Please describe barriers that your office or program has encountered to obtain access to death data. This was an open text question. According to the responses, we categorized the answers into 4 different categories: Lag Time, Confidential Issue, Complex User Agreement Process, and Systemic/ Technology Issue. There was a 59.6% response rate, with 36 responses missing.

**Figure 21.** The following figure shows the percentage of answers for Question 25.

**Question 26:** Additional Comments. This was an open text question. The following table shows the additional comments.

**Table1. Additional Comments**

|  |  |
| --- | --- |
|  | **Additional Comments** |
| **1** | The state vital records data is aggregate and not useful for all causes of death. They feature tables that are not as comprehensive for causes of death needed (types of death: drug overdose/substance abuse etc. and sub county) |
| **2** | More work around death certificate language as it translates to ICD codes would be more helpful than access. |
| **3** | It would be interesting to have a "mortality dashboard" with real time death data through Epi Info 7 or some other statistical software. |
| **4** | What is really upsetting is that the State sends us paper copies of the data, so we know what is going on, but largely refuses to send digital copies. |
| **5** | Not want to share data because of HIPPA |

**Section8. Comparing results for different types of data.**

**Figure 22.** The following figure compares jurisdiction accessibility by different types of death data.

**Figure 23.** The following figure shows the comparison in how interested jurisdictions are in receiving different types of death data.

**Section9. Summary of Analysis:**

A total of 26 questions were asked to gather information on accessibility to different types of death data, timeliness of data flow, uses of death data as well as barriers to obtain access death data. Eighty-nine participants completed this questionnaire. The participants were from 22 different states and 66 different counties/jurisdictions. Among the 22 states who responded, Florida, Massachusetts, Arizona, Virginia, Kentucky had the most number of response frequency. We also got responses from the following states: California, Oregon, Washington, Nevada, Colorado, Kansas, Texas, Missouri, Illinois, Wisconsin, Michigan, Ohio, Pennsylvania, New York, Connecticut, Georgia and North Carolina. Among the states that did not respond to the survey, most were in the north middle and south middle regions of the United States. Sixty-six counties responded to the survey. Arizona and Florida had the most county responses, with 11 (73.3%) counties from Arizona and 29 (43.3%) from Florida.

From the comparison Figure 22 and Figure 23, the most two frequently received data sets by local health departments were individual identifiable death record data 28 (35%) and aggregate statistics/ report on death data 32 (41.6%). Among the four different types of death data, 43 (48.3%) participants were interested or very interested in receiving real-time death data, while 39 (43.8%) participants were interested or very interested in receiving de-identified death data. Most local health departments have use death data for case investigation, disease surveillance or mortality analysis (N=46, 72%). During the survey participants were also asked about the barriers to obtain access to death data, the most common barrier for using the death data was lag time (N=23, 56%). Besides the four death data types that we asked about in the survey (real-time or live data, individually identifiable death data, de-identified death data, aggregate statistics), 6 (43%) local health departments indicated they also receive individual death certificates as well.

The current proposed goal for the Robert Wood Johnson Foundation quality improvement project is to have individually identifiable death data available to local health departments at least quarterly. In order to determine the proportion of survey respondents that would benefit from the project as currently proposed, we excluded the number of respondents who have access to live data (n=26) and the number of respondents that receive individually identifiable data at least quarterly (n=8). In summary, we estimate our proposed project would benefit 62% (n=55) of respondents.

If we could have de-identified death data available to local health departments at least quarterly, we would benefit 65.2% (n=58) of respondents. If we could have the aggregate statistics or reports on death data available to local health departments at least quarterly, we would benefit 68.5% (n=61) of respondents.